

Links (by subject) – Resources provided in the chat

Diagnosis of ME/CFS from

IOM/NAM 2015 (clinical diagnosis): https://www.nap.edu/resource/19012/MECF5_ProposedDiagnosticCriteria.jpg

DePaul Symptom Questionnaire PEM short form:

<https://leonardjason.files.wordpress.com/2021/06/dsq-short-form-pem-questionnaire.pdf>

Resources for PT/OTs

Facebook group for PTs and OTs (Sallie Rediske and Melinda Maxwell):

<https://www.facebook.com/groups/3049027761780369/?ref=share>

<https://world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL.pdf>

Finding anaerobic threshold and heart rate monitoring

<https://workwellfoundation.org/wp-content/uploads/2021/03/HRM-Factsheet.pdf> (also noted: recommendation given here is a starting point. Patients need to adjust it as needed for them individually. The pairing of Workwell's Heart Rate Monitoring Fact sheet guidelines, their PEM Timecourse and Rate of perceived exertion (which is a scale easy to obtain on the web) which should remain in the very light or light level are great ways to begin to get a good handle on PEM. These tools are just to provide guidelines. Everyone's symptoms are going to be unique.)

<https://workwellfoundation.org/wp-content/uploads/2020/09/Top-Energy-Saving-Tips.pdf>

<https://workwellfoundation.org/wp-content/uploads/2020/03/WW-PEM-Timecourse.pdf>

Oximeter, one source <https://www.walgreens.com/store/c/walgreens-fingertip-pulse-oximeter/ID=prod6089451-product>

Other symptoms

Leonard Jason of DePaul University found that 29% of ME/CFS patients experienced **paralysis**.

<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC6468435/> — this is something PT/OTs need to know.

For **cognitive testing** see this article <https://www.massmecfs.org/more-resources-for-me-cfs/395-dr-gudrun-lange-reviews-neuropsychological-testing-for-cfs-and-fm> - I would emphasize that neuropsychological testing for these illnesses must be performed by a tester who can interpret the test from the understanding of ME/CFS and associated illnesses. Ignorant testers will come up with a psychiatric/psychological diagnosis. These knowledgeable testers are rare. Also the testing may be expensive.

Websites for more information

<https://workwellfoundation.org/>

<https://longcovid.physio/>

<https://www.omfcanada.ngo/people/alain-moreau/>

<https://ammes.org/organizations/>

<https://solvecfs.org/me-cfs-long-covid/patient-and-caregiver-resources/>

General resources to share with health care providers

US Clinician's Coalition Treatment Guidelines, NICE 2021, IOM, Workwell's one page statement against GET

<https://workwellfoundation.org/wp-content/uploads/2019/07/MECFS-GET-Letter-to-Health-Care-Providers-v4-30-2.pdf>

The American Academy of Physical Medicine and Rehabilitation (AAPM&R) Multi-Disciplinary PASC Collaborative produced **consensus guidance for Long COVID that recognizes PEM** and the need to pace and not exceed limits in those with PEM. It's not perfect by any means but might help get them to consider PEM because of the group that authored it. You'd want to read it first to make sure it works for you. <https://onlinelibrary.wiley.com/doi/full/10.1002/pmrj.12684>

This is a free 1-hour CME about ME/CFS that you can refer your provider to if they want to learn: https://ceitraining.org/courses/course_detail.cfm?medialD=872#.YeSY4uROnDv

How you can get involved (studies and advocacy)

Share your story with Rep. Ayanna Pressley (MA): Recently Rep. Ayanna Pressley (MA) asked patients to share both their experiences with Long Covid and what would help the patient community. — And Rep. Alexandria Ocasio-Cortez (NY), who is recovering from Covid, mentioned LC (chronic fatigue, POTS) in her Insta and Fb posts yesterday - Both are opportunities to educate legislators on the need for physician education, more providers, less siloed healthcare, research, and financial support for patients suffering from these long-ignored syndromes - POTS, ME/CFS, MCAS, etc, and post-viral syndromes in general. — I hope many of us can help advance this dialogue by reaching out to them.

To respond to Ayanna Pressley, click here:

<https://twitter.com/ayannapressley/status/1481737054484586498>

Stanford Synder lab study. We need more studies for Chronic illnesses incl those that have PEM, Crashes. Thus Professor Snyder at Stanford Snyder lab has funding to do wearables, blood sample etc for 2 years for crashes:

<https://snyderlabs.stanford.edu/crashcourse/>

150 patients with moderate ME

150 with chronic Lyme
150 with Long Covid/PACS

They are seeking enrollees in this and will provide fit bit and can do in-home small blood samples with Tasso, so no trips or Phlebotomists.

The RECOVER Initiative, which is the NIH funded study of Long Covid, has sites in Massachusetts including Brigham and Womens. If you're interested in being involved, you can get more information as they recruit by filling out this form.

<https://openredcap.nyumc.org/apps/redcap/surveys/?s=TYCLM7PE97>

Enroll in AllofUS. So that people with ME/cfs, FM, POTS, Chronic Lyme, Long Covid, PAPIS, PASC become better studied, consider enrolling in "AllofUS" <https://www.joinallofus.org/> by HHS that will study 1 million Americans that are over 18, for 10 years. Then we will have better representation and be less ignored by Feds, NIH, CDC etc. You will get blood & urine sample at a medical center and eventually will get your full genome. 3 in our family got sampled at UCSF. You just might wait until Covid Omicron settles, and not recommended for severe ME unless Caregiver can help.

Join the SolveME You+ME Registry. To get more great data for ME/cfs and PASC, consider registering with SolveME registry for these two closely related illnesses. See <https://youandmeregistry.com/> and hope you can join 5700 including controls.

For people worldwide, www.diseasemaps.org does list over 1000 diseases, incl "Chronic Fatigue Syndrome / M.E." and other illnesses, where people can self report and seek best local MDs, support groups, and advocate together. I have found this website that is International, useful at times.